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Recreational Manual for Caregivers of Individuals with Cerebral Palsy

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RECREATIONAL MANUAL FOR CAREGIVERS OF INDIVIDUALS WITH
CEREBRAL PALSY

by

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Advisor: Gail Bass, Ph.D., OTR/L

A Scholarly Project

Submitted to the Occupational Therapy Department

of the

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In partial fulfillment of the requirements

for the degree of

Master's of Occupational Therapy

Grand Forks, North Dakota
May 13, 2006



This Scholarly Project Paper, submitted by Erica Bucher in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Heidi Bass PhD, OTR/L
Faculty Advisor

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Date

PERMISSION

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Department Occupational Therapy

Degree Masters of Occupational Therapy

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ABSTRACT

A brief literature review was conducted on cerebral palsy to gain general information and statistics. After reviewing the literature, it was noted that there is a significantly high number of children diagnosed with cerebral palsy each year. These individuals are at a high risk to experience the lack of opportunity for a wide choice of recreational activities. To understand the magnitude of the problem an extensive literature review was done on this topic. It was found that the lack of access and participation in independent recreational opportunities may lead to the development of dependent behavioral patterns, learned helplessness and depression.

The purpose of this project was to develop a manual for parents and caregivers of individuals with cerebral palsy. The manual was designed to inform the reader about cerebral palsy, focusing specifically on its influence on the access and participation in recreational activities. It is hoped that through the information and resources that are included in the manual, caregivers will understand the importance and benefits of recreational opportunities for their child or adolescent with the diagnosis of cerebral palsy.

The manual is caregiver-friendly and written so that it is easily understood by the general population that will be reading it. The preface of the manual introduces the purpose and what the reader will find in the manual. The manual is organized into four easy to follow chapters. The first chapter includes an introduction to cerebral palsy. It addresses the medical aspects, as well as the functional aspects that are affected in an

individual who has a diagnosis of cerebral palsy involvement. The second chapter of the manual looks at the occupational and therapeutic aspects of cerebral palsy. It describes the relationship of the occupational therapy framework to recreation and leisure. The third chapter breaks down various recreational opportunities in terms of its history, the benefits of the activity, the equipment needed, the appropriate modifications/adaptations and examples of each opportunity. Chapter four includes caregiver resources for organizations and equipment that will help the child access and participate in recreational opportunities. The manual was designed as a resource for occupational therapists to give other health care professionals and to parents and caregivers of children and adolescents with cerebral palsy.

CHAPTER I

INTRODUCTION

Occupational therapists are skilled in helping children and adolescents with cerebral palsy gain the highest possible level of participation in areas of occupation; one of the areas of occupation is recreation and leisure. According to Weiss, Bialik, and Kizony (2003), "Individuals with cerebral palsy are at a high risk to experience the lack of opportunity in independent leisure activities" (p. 335). Because cerebral palsy is a life-long disability, one of the greatest challenges for the health care team is to provide social support and access to activities they enjoy, as well as medical services for individuals with cerebral palsy.

To understand the magnitude of the problem, an extensive literature review was done on the topics of cerebral palsy and recreation opportunities for individuals with physical disabilities. It was found that there is limited research and literature on the recreation opportunities for an individual with cerebral palsy and the resulting impact on their physical and psychosocial development. According to the research, cerebral palsy afflicts 1.4-2.4 children per 1000 live births (Rogers, 2005, p. 176). Based on the literature review in Chapter II, it was also found that: 1) a child's caregivers should understand the unique needs and requirements of their child who has cerebral palsy, 2) public perceptions of cerebral palsy often contain misunderstood or inappropriate ideas, and 3) these misconceptions about cerebral palsy can limit recreational opportunities for individuals with cerebral palsy (Feldman, Krueger, Neyhart, and McAbee, 2002).

The Ecological Model of Human Performance was chosen to guide the process of developing the final project because it uses a client-centered approach that can be adapted to each individual's needs. It separates each activity into the sub-categories of: person, context, task, and the performance and how each affects the activity (Dunn, Brown & Youngstrom, 2003). The end product is a caregiver friendly recreational manual. It is client-centered as each individual is able to identify and participate in activities they are interested in. The manual also breaks down the task and offers appropriate modifications to allow the individual to achieve the highest performance in that activity.

This paper includes five chapters; this chapter is introductory and defines the problem of the study and the proposed product. Chapter II is a review of current literature and research; it has an overview of current information about cerebral palsy and the physical aspects of the diagnosis that have an influence on access and participation in recreational opportunities. The chapter also contains information on the importance of recreation and leisure activities for individuals with disabilities; Chapter III is a detailed description of the process used in designing the manual. The end manual for caregivers is presented in its entirety in Chapter IV. Chapter V is a summary of the project as a whole, including recommendations for additional research and implementation of the manual.

CHAPTER II

REVIEW OF LITERATURE

“Cerebral palsy is a disorder in development due to nonprogressive central nervous system deficits that are manifested by impaired ability to move and maintain posture and balance.” (Colangelo & Gorga, 1996, p. 3)

The Child with Cerebral Palsy

Medical Aspects

According to Rogers (2005), cerebral palsy is a result of injury to or abnormal development of the brain. Cerebral palsy afflicts 1.4-2.4 children per 1,000 live births. “It is estimated that 5,000 infants and 1,200 to 1,500 preschool children are diagnosed with cerebral palsy each year” (p. 176). In many cases, the exact cause of this injury is not known. Benda, McGibbon and Grant (2003) write

(Cerebral Palsy occurs) as a result of an injury occurring *in utero*, at birth, or within the few first months of life, neurologic lesions in the brain result in abnormalities of muscle tone, reflexes, and righting reactions, as well as impaired motor development (pp. 817-818).

There are several explanations for the cause of cerebral palsy; the central nervous system damage can occur during pregnancy (*in utero*), during the birth process, or during childhood.

In utero damage (congenital) may be related to genetic or chromosomal problems, or complications related to labor and delivery. Maternal infections such as cytomegalovirus, syphilis, or varicella virus or exposure to environmental toxins can also affect how the fetus grows in terms of receiving the blood, oxygen and nutrients for

growth. “Prematurity now accounts for the majority of known causes for cerebral palsy” (Rogers, 2005, p. 176). Infants that are born before they are full term are at risk for intraventricular hemorrhages (IVH), which in turn may cause cerebral palsy (United Cerebral Palsy Research and Educational Foundation, 1991). Rogers (2005) notes that these infants are also at risk because their nervous system is more vulnerable to insult “(i.e., increased sensitivity to bleeding near the lateral ventricles, which has a cascading effect on further central nervous system development)” (p. 176).

Cerebral palsy may occur within the first couple years of life, and is described as acquired cerebral palsy. Acquired cerebral palsy etiology is usually caused by brain damaged from a serious illness’ or accidents. Accidents that may cause cerebral palsy include brain injuries, such as, from a fall, or from a near drowning incident where there is not enough oxygen getting to the brain tissue (Rogers 2005).

According to Colangelo and Gorga (1996), cerebral palsy has a major impact on posture and movement, but Finnie (1997) notes that there may also be secondary impairments. Secondary impairments may include but are not limited to learning disorder, visual impairments, speech and language problems, or hearing impairments. About half of the individuals with cerebral palsy have a mild to a severe learning disorder. These learning disorders may be in a variety of forms. For example, an individual may have dyslexia, or problems with mathematics, but be good at several other things (Finnie, 1997). Half of the population will also have some type of visual impairment. A small proportion of individuals with cerebral palsy have damage that affects the nerves that run from the eyes to the part of the brain that interprets the signals, thus leaving the individual blind. Because cerebral palsy is a movement disorder

that often affects the muscles of the eyes, a large portion of this population is likely to squint, which also causes further visual impairments (Finney, 1997). Other muscles that may become affected by cerebral palsy are the neck muscles. This muscle involvement may influence the tone and volume of the individual's voice as well as cause instability and decreased coordinated movements of the tongue and jaw. These limitations may cause drooling, and possible limitations in communication (Rogers, 2005). Individuals with cerebral palsy may also have some level of hearing loss. (Box, 1997).

The following section is a description of the three primary classifications of cerebral palsy.

Primary Classifications of Cerebral Palsy

The individual with cerebral palsy has affected development, difficulty moving, poor quality of movement patterns, and poor posture and balance. Cerebral palsy is usually characterized by muscle tone fluctuations causing the individual to make unwanted movements, or leaving the individual with weak, stiff limbs. Cerebral palsy is global diagnoses that can present in many different forms. Each case of cerebral palsy affects a child differently, and some have more than one form of cerebral palsy (also described as mixed cerebral palsy (Rogers, 2005). The three primary classifications of cerebral palsy are spastic, athetoid, and ataxic.

Spastic cerebral palsy is the most common form and affects the body's ability to relax muscles, causing tightness and difficulties in movement. Spastic cerebral palsy can be mild to severe in form, and can affect all four limbs, both arms or legs, or only one side. Spastic cerebral palsy indicates that there is a lesion in the motor cortex, causing high tone or "spastic" muscle tone. The distribution of muscle tone in spastic cerebral

palsy varies. If the child has severe spasticity all four limbs are generally involved and hemiplegic distribution, one side of the body, is generally seen in the child with mild spasticity. Some personality traits that are characteristic of individuals with spastic cerebral palsy include: passivity, dependency, resistance to change, and anxiousness/fearfulness of movement. Children with high tone or spasticity have difficulty initiating movement and the overall tone may increase with increased effort, especially in children with severe spasticity (Rogers, 2005).

According to Rogers (2005), Athetoid cerebral palsy affects the ability to control muscles, leading to involuntary and uncontrolled movements in the affected muscles; it is a result of a lesion in the basal ganglia. Athetoid cerebral palsy causes fluctuations in the muscle tone; a child with athetoid cerebral palsy is constantly making unwanted movements even when trying to relax or sit still (Box, 1997). The distribution of tone in the individual with athetoid cerebral palsy usually affects all four limbs, but may only affect one side of the body. Individuals with athetoid cerebral palsy are usually more outgoing and less fearful, but tend to get frustrated more easily than their peers with spastic or ataxic cerebral palsy. (Rogers, 2005).

Rogers (2005) describes the individual with ataxic cerebral palsy as having incoordination and poor stability; this type is also characterized by tremors at rest. Ataxic cerebral palsy occurs when there is cerebellar damage. An individual with ataxic cerebral palsy has difficulty making precise movements and they often appear as clumsy or awkward when making voluntary movements. The individual with ataxic cerebral palsy usually has involvement of all four limbs. This individual needs a wide base of

support to maintain balance and generally does not like activities that require them to move.

Public Awareness

Public perceptions of cerebral palsy often contain misunderstood or inappropriate ideas. Feldman, Krueger, Neyhart, and McAbee (2002), address this concern in their study of 100, mostly educated, upper to upper-middle class adults and their perceptions of cerebral palsy. The adults were asked twenty questions about cerebral palsy, its prognosis, and other associated limitations. The adults' responses suggested that there were many individuals that had several misconceptions about cerebral palsy. Some of the misconceptions that a large percentage of the population shared include a belief that the disorder has a genetic etiology (40%), children with cerebral palsy can not speak (20%), they die earlier than unaffected children (57%), and they cannot hold jobs as adults (20%) (p. 471).

A small percentage of the adults' responses included even more detrimental misconceptions. These include the belief that cerebral palsy is infectious (4%), and the belief that parents should restrict their children from associating with those affected (3%). (Feldman et al., 2002, p. 471)

Occupational Therapy and Cerebral Palsy

Treatment of individuals with cerebral palsy should be done by a multidisciplinary team and an occupational therapist should be a member of that team. Parents are always a part of the team and other members may include a primary physician, a physical therapist, and a speech language pathologist. Occupational therapy would be beneficial to an individual with cerebral palsy because the occupational

therapist looks at many aspects of the individual's life. (American Occupational Therapy Association [AOTA], 2002) After receiving the referral from the physician, the occupational therapist must first determine if the referral is appropriate. According to Colangel and Gorga (1996), "this may include: reviewing written and verbal information about the client; identifying functional activities that the client can and cannot perform or is having difficulty performing; taking a brief client history; determining the client's/family's needs and plans" (p. 5). The occupational therapist's goal is to help the individual obtain their own stated functional goals across the contexts. In order to obtain these goals, occupational therapists use the *Occupational Therapy Practice Framework: Domain & Process* (AOTA, 2002) as a guide for assessment and intervention.

The *Occupational Therapy Practice Framework: Domain and Process* was "developed to more clearly affirm and articulate occupational therapy's unique focus on occupation and daily life activities and the application of an intervention process that facilitates engagement in occupation to support participation in life" (AOTA, 2002, p. 609). The framework addresses many areas of an individual's life including; the various life activities in which people engage (areas of occupation), the observable features of what the individual does (performance skills), the behaviors that are habitual or routine (performance patterns), the conditions within and surrounding the individual that influence function (context), the aspects of the activity (activity demands), and the factors that reside within the individual that affect performance (client factors). Based on the framework one outcome of occupational therapy intervention is to increase each client's quality of life (AOTA, 2002).

Client Factors

The *Occupational Therapy Practice Framework: Domain and Process* describes the client factors that reside within the individual and affect performance in areas of occupation, such as leisure. These client factors include body functions and body structures and how they influence the way an individual carries out an activity (AOTA, 2002).

There are a number of client factors that are important to consider during leisure activities. These factors include mental, sensory, respiratory, cardiovascular, skin structure, and neuromusculoskeletal functions. Mental functions include affective, cognitive and perceptual processes. Sensory functions are considered when looking at sight, hearing, pain, touch, proprioception and vestibular input from each leisure activity. Respiration and heart rate should also be monitored when the leisure activity demands a large amount of energy output. Skin structure provides a protective layer for underlying organs. Participation in leisure activities may also require neuromusculoskeletal, or movement related functions. These include the functions of joints, bones, muscles and the corresponding movements (AOTA, 2002).

Quality of Life

Bjornson and McLaughlin (2001) did a study on the measurement of health-related quality of life in children with cerebral palsy. The authors write that, “quality of life is one of the high priority goals of current research sponsored by the UCPA (United Cerebral Palsy Association)” (p. 183). Bjornson and McLaughlin divided their perception of quality of life into three categories:

- (1) basic survival including health care and maintenance, anticipation and prevention of secondary health problems, and

activities of daily living; (2) productivity and meaningful existence including education, vocation, avocation, community participation and family life; and (3) social and work relationships including the emotional, cognitive and social participation in work, play, social, family, and sexual relationships. (p. 184)

According to Benda et al. (2001), although the central nervous system lesions in cerebral palsy are static, the dysfunction can be progressive. The individual is motorically impaired and usually has some postural asymmetries. This imbalance can lead to dysfunctional bone growth and can lead to further disabilities. The authors note, "...therapy helps decrease the impact of multiple impairments while simultaneously improving postural alignment and motor skills, fundamental for energy-efficient, pain-free movement and play" (p. 818).

When an individual engages in occupations that provide them with a sense of productivity and meaningful existence, it contributes to a perception of higher quality of life. This meaningful existence can be found in the form of education, vocation, etc., and relationships established throughout all environments and contexts will also increase the individual's perception of higher quality of life. These relationships can be formed in social, work, or leisure contexts. (Bjornson & McLaughlin, 2001).

Recreation & Leisure

One way the health care team can address the quality of life topic is by looking at all areas of the individual's life, including therapeutic leisure and recreational activities. The discipline of occupational therapy is well suited for this role. Leisure is one of the areas of occupational performance described in the *Occupational Therapy Practice Framework: Domain and Process* which looks at the occupations one engages

in during recreation and leisure activities. (AOTA, 2002). Because this project has a focus on recreation and leisure, other areas of occupation will not be described.

There is not a lot of literature that addresses recreation and leisure specifically for individuals with cerebral palsy, some of the literature on recreation and leisure for individuals with general disabilities can be applied to the population with cerebral palsy. Because cerebral palsy is a life-long disability, one of the greatest challenges for the health care team is to provide social support and access to activities that individual with cerebral palsy enjoy, as well as medical services. Weiss et al. (2003) write that, “The pervasive lack of opportunity for a wide choice of independent leisure time activities may lead to the development of dependent behavioral patterns, learned helplessness and depression” (p.336). The authors also note that some therapeutic recreational activities that are normally done in the medical setting can be done in a social/natural setting; individuals are generally more motivated when these activities are done in the natural setting (Weiss et al., 2003). By incorporating recreational activities that are therapeutic into the individual’s life it would concurrently help prevent further disability and maintain current level of functioning as well as sustain the individual’s interest and enthusiasm during a therapeutic activity (Benda et. al, 2003).

Recreation and Leisure Activities

The client factors, that were described earlier in this chapter, will influence the participation and type of involvement in the recreation and leisure activities an individual with cerebral may choose to participate in. The following section describes a variety of recreation and leisure activities that are available to the individual with cerebral palsy.

Athletics

Athletics provide a natural therapeutic activity for individuals with cerebral palsy. In his article, Banta (2001) notes that there are other apparent benefits of athletics other than the physical. He states that, “(One can) witness first hand the growth in self-confidence, enhanced self-image, and all-round maturity that accompanies young people participating in these activities.”(p. 147). There are numerous sports that can be modified and adapted to fit the abilities of individuals with cerebral palsy. The level of involvement in terms of the disability will decide how much modification or adaptation is required for the individual’s participation. It was in 1980 that athletes with cerebral palsy were included in the Paralympic games. A young track and field athlete who is autistic that won two gold medals at the games helps explain the difference between “normal” individuals and individuals with autism to a sports writer: “Autism is very strange. Everyone assumes we’re a bit simple but that’s not true. My brain is simply wired up differently. I don’t see or hear the world in quite the same way as you do.” (Banta, 2001, p.147) The American Academy of Orthopaedic Surgeons recognized the positive impact of sports on individuals with disabilities in 1983 (Banta, 2001).

Music therapy/music enjoyment

Music may be used as a therapeutic medium, or purely for enjoyment. From the beginning of life, all humans are exposed to music. Thorton (1997) states, “For nine months (the baby) heard the rhythmical beating of his mother’s heart; her breathing; her voice rising and falling in phrases and patterns and he felt the rhythmical movements of her body” (p. 125). Even while in the womb, the individual hears “music”. Because music is a familiar thing, even for infants, it can be used for relaxation, or stimulation.

Music therapy is a specialized intervention used by trained therapists to interact with individuals. This type of intervention can be used with both the young and old alike. The goal of music therapy is to build a relationship with the individual, through the use of proper musical equipment. This informal relationship may help bridge the sense of loneliness that often emerges when an individual has a debilitating condition (Thorton, 1997).

During music therapy, the individual's signals are responded to by the therapist. It is the job of the therapist to respond to the individual and make appropriate changes to the music accordingly. By doing so, the individuals actions end up becoming intentional and meaningful. Thorton (1997) helps explain this by informing her reader that "a stereotypical action may end up becoming meaningful if responded to as having a musical meaning". (p. 126)

Hippotherapy/horseback riding

Documentation of the benefits of horses to health has existed since the fifth century BC (Benda et al., 2001). According to Sterba, Rogers, France and Vokes, (2002), horseback riding can result in improvements in many areas, including: standing, quadruped balance, arm and leg coordination and posture. Equine-assisted therapy is a treatment intervention that utilizes the multidimensional movement of a horse during the therapy session. Equine-assisted therapy is often referred to as hippotherapy. Hippo comes from the Greek word "hippos", which means horse (American Hippotherapy Association, 2005). Hippotherapy has been used in the United States for decades in the treatment of a variety of diagnoses, including cerebral palsy. According to Benda et al. (2001), it is a "treatment strategy in which the movement of the horse is used to improve

posture, balance and overall function” (p. 818). As with many other creative therapy activities, it has the benefit of producing engagement and motivation in the individual. Benda et al. (2003), state that “hippotherapy provides physical, cognitive, emotional, and social stimulation as well as nurturing and developing capabilities that may be untapped through conventional treatment” (p. 823).

Virtual Reality

Due to physical deficits, the individual with cerebral palsy may be limited in terms of what kind of occupations and the frequency in which they can participate in those occupations. These limitations may compromise an individual’s perception of self-efficacy and self-competence (Miller and Reid, 2003). Miller & Reid (2003) state, “Whether due to sensory impairments, limitation in voluntary movement or mobility as well as environmental barriers, these children may experience limited opportunities to explore the world around them through engagement in play behaviors” (p.623).

Virtual reality can give individuals with cerebral palsy a safe way to challenge their abilities and explore other leisure opportunities, while surpassing environmental barriers. Miller and Reid (2003) did a study on the personal experiences of children with cerebral palsy engaging in a virtual reality play intervention program. A few of the participants commented that they discovered abilities that they did not know they initially had. A nine year old girl in the study stated “I feel that I’ve, I’ve grown to learn about my arm and I could do more things to help my arm go a bit better and I could use my arms more...and probably like in real life when I grow up I might like probably need this arm a lot” (p. 628). According to Miller & Reid, their participants reported perceived physical changes and increased social acceptance from family as well as peers after

participation in virtual reality intervention tools. Virtual reality can provide the three-dimensional, real-time activity that change in response to movements. Miller & Reid also purposed that an individual who is willing to participate in virtual reality interactions will be more willing to try other approaches and seek out new challenges. Recent advancement in technology provides the opportunity to engage in occupations that may not be available to individuals with major physical involvement. There are many advantages to virtual reality. Some of the biggest advantages, beyond the accessibility factors, include the ability to change the environment easily, to grade specific tasks, and to adapt the task as needed according to the individual's capabilities (Weiss, Bialik, & Kizony, 2003). Miller & Reid (2003) include a quote from a twelve-year old boy with spastic cerebral palsy about his thoughts on virtual reality, "It's kinda, it's therapy, likes it's therapy, but, um, you don't know it's therapy because once you get into it's really fun and you forget about doing it and stuff"(p. 628). This quote demonstrates that this type of intervention may be meaningful to individuals with cerebral palsy and increase their investment in the activity.

One example of a virtual reality system is VividGroup's Gesture Xtreme video capture virtual reality system. Gesture Xtreme was originally developed for science museums, but in recent years has actually been used in therapy treatment sessions. It provides the opportunity for the individual with the disability to participate in numerous environments; the therapist can grade the activity according to the individual's capabilities, and also has the ability to produce a report of performance. Gesture Xtreme uses the individual's whole body as the input device. All movements in the virtual environment are controlled by the individual's movements and the individual is

encouraged to use all their body parts for movement control. Finally the therapists can verbally, as well as physically, guide the individual through the environment. (Weiss et al., 2003)

The literature reviewed in this chapter indicates that there is a demand for increased exposure to augmented leisure activities for individuals with disabilities. These leisure activities have positive correlation between self-perceived abilities, self-concept and self-competence. Skills obtained from participation in these activities may be incorporated into lifelong recreational opportunities.

CHAPTER III

ACTIVITIES/METHODOLOGY

Because of my interest in recreation and leisure activities for individuals with disabilities, I did an initial review of literature on the topic of recreation and leisure activities for individuals with disabilities. This early review of literature showed that there was not a great deal of research or literature in this specific area. What was found was that the general public has some misconceptions about cerebral palsy; and that due to the lack of informative information, individuals with cerebral palsy are at a higher risk of experiencing negative consequences. Many areas of occupation are impacted by a diagnosis of cerebral palsy and one area that is often overlooked in intervention is access and participation in recreational opportunities. In response to this problem, my product for this scholarly project was to develop a comprehensive and reader-friendly recreational manual for caregivers of individuals with cerebral palsy. The manual was designed for occupational therapists as a resource to give to caregivers. The purpose of the manual is to educate caregivers about cerebral palsy and the impact it may have for their child or adolescent on access and participation in recreational activities.

In order to obtain the information required to design an end product that is informational and comprehensive, an extensive literature review was completed. Research and literature in the area of the medical and physical aspects was reviewed in order to develop the overview of cerebral palsy for the manual. The rest of the literature review had its focus on recreation and leisure including: athletics, music therapy/music

enjoyment, hippotherapy/horseback riding, and virtual reality. The contents of the manual, that is included in its entirety in Chapter IV of this document, are based on the research and literature reviewed in Chapter II and current resources about recreation activities and adaptive equipment.

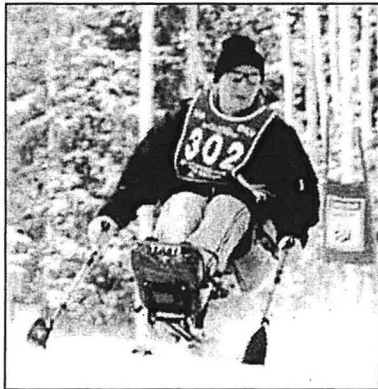
CHAPTER IV

PRODUCT

Information obtained through the literature review was foundational to the development of a recreational manual for caregivers of individuals with cerebral palsy. The manual includes an overview of cerebral palsy and the implications of the diagnosis and a description of the benefits of participation in recreational activities, but the major focus is on recreational activities and corresponding resources. The information is presented in care-giver friendly form, with limited medical jargon.

This recreational manual for caregivers of individuals with cerebral palsy was developed as a resource for occupational therapists to give to parents and caregivers to help them gain knowledge and resources regarding access and participation opportunities in recreational and leisure activities for their child or adolescent. It is the author's intent that therapists introduce the manual after the child has an initial evaluation, so they can discuss what activities may be appropriate for the child. This manual facilitates communication and interaction between the occupational therapist, child, and family about the importance of recreational activities; it also has information on accessing and participating in such activities.

RECREATION MANUAL FOR CAREGIVERS OF INDIVIDUALS WITH CEREBRAL PALSY



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PREFACE

Being a caregiver for an individual with cerebral palsy is a difficult job for anyone, and can seem overwhelming at times. There are many things to consider when caring for an individual with cerebral palsy, and the important area of recreation and leisure can be easily overlooked. This manual was designed to help you as parents or caregivers of a child or adolescent with cerebral palsy identify and access appropriate recreational opportunities for your child.

Chapter I of this manual is a brief introductory section on cerebral palsy. Chapter II focuses on the benefits of recreational opportunities and what to consider for your particular child. Chapter III of the manual includes details about various recreational activities. Each activity includes sections on its corresponding history, what your child needs to be able to do to participate, the benefits of the activity, the equipment required, what your child will do in the activity, and then some appropriate modifications of that activity. Chapter IV includes a variety of resources you can utilize when looking at issues having to do with access and participation in recreational activities for your child or adolescent. These resources are separated into organizations and into equipment suppliers.

If you have questions or need further information feel free to contact the therapist who gave you this manual.

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CHAPTER 1

INTRODUCTION TO CEREBRAL PALSY

THE CHILD WITH CEREBRAL PALSY

“Cerebral palsy is a disorder in development due to non-progressive central nervous system deficits that are manifested by impaired ability to move and maintain posture and balance” (Colangelo & Gorga, 1996, p. 3). This means that cerebral palsy does not get worse with time, but your child will have difficulty with moving about his or her environment.

You are not alone. Cerebral palsy afflicts 1.4-2.4 children per 1000 live births (Rogers, 2005, p. 176). It is estimated that 5,000 infants and 1,200 to 1,500 preschool children are diagnosed with cerebral palsy each year (Rogers, 2005, p. 176).

In many cases, the exact cause of this injury is not known. Benda, McGibbon and Grant (2003) write

(Cerebral Palsy occurs) as a result of an injury occurring *in utero*, at birth, or within the few first months of life, neurologic lesions in the brain result in abnormalities of muscle tone, reflexes, and righting reactions, as well as impaired motor development (pp. 817-818).

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The individual with cerebral palsy has affected development, difficulty moving, poor quality of movement patterns, and poor posture and balance. Cerebral palsy is usually characterized by muscle tone fluctuations causing the individual to make unwanted movements, or leaving the individual with weak, stiff limbs. Cerebral palsy is global diagnoses that can present in many different forms. Each case of cerebral palsy affects a child differently, and some have more than one form of cerebral palsy (also

described as mixed cerebral palsy (Rogers, 2005). The three primary classifications of cerebral palsy are spastic, athetoid, and ataxic.

Spastic cerebral palsy is the most common form and affects the body's ability to relax muscles, causing tightness and difficulties in movement. Spastic cerebral palsy can be mild to severe in form, and can affect all four limbs, both arms or legs, or only one side. Spastic cerebral palsy indicates that there is a lesion in the motor cortex, causing high tone or "spastic" muscle tone. The distribution of muscle tone in spastic cerebral palsy varies. If the child has severe spasticity all four limbs are generally involved and hemiplegic distribution, one side of the body, is generally seen in the child with mild spasticity. Some personality traits that are characteristic of individuals with spastic cerebral palsy include: passivity, dependency, resistance to change, and anxiousness/fearfulness of movement. Children with high tone or spasticity have difficulty initiating movement and the overall tone may increase with increased effort, especially in children with severe spasticity (Rogers, 2005).

According to Rogers (2005), Athetoid cerebral palsy affects the ability to control muscles, leading to involuntary and uncontrolled movements in the affected muscles; it is a result of a lesion in the basal ganglia. Athetoid cerebral palsy causes fluctuations in the muscle tone; a child with athetoid cerebral palsy is constantly making unwanted movements even when trying to relax or sit still. The distribution of tone in the individual with athetoid cerebral palsy usually affects all four limbs, but may only affect one side of the body. Individuals with athetoid cerebral palsy are usually more outgoing and less fearful, but tend to get frustrated more easily than their peers with spastic or ataxic cerebral palsy. (Rogers, 2005).

Rogers (2005) describes the individual with ataxic cerebral palsy as having incoordination and poor stability; this type is also characterized by tremors at rest. Ataxic cerebral palsy occurs when there is cerebellar damage. An individual with ataxic cerebral palsy has difficulty making precise movements and they often appear as clumsy or awkward when making voluntary movements. The individual with ataxic cerebral palsy usually has involvement of all four limbs. This individual needs a wide base of support to maintain balance and generally does not like activities that require them to move.

Public perceptions of cerebral palsy often contain misunderstood or inappropriate ideas. Misconceptions of cerebral palsy can influence the individual with the diagnoses by limiting your child's involvement in every day activities. This manual will provide you information regarding the types of recreational opportunities and organizations that your child can participate in.

CHAPTER 2

BENEFITS OF RECREATIONAL ACTIVITIES

HOW PARTICIPATING IN RECREATIONAL ACTIVITIES CAN HELP YOUR CHILD AND WHAT TO CONSIDER

Because cerebral palsy is a chronic disability, it will always be a part of your child's life. It is important for the development of your child that they are able to have social support and access to activities they enjoy, as well as having access to medical services. Weiss et al. (2003) write that, "The pervasive lack of opportunity for a wide choice of independent leisure time activities may lead to the development of dependent behavioral patterns, learned helplessness and depression" (p.336). Some therapeutic recreational that are normally done in the medical setting can be done in a social/natural setting; individuals are generally more motivated when these activities are done in the natural setting (Weiss et al., 2003).

By incorporating recreational activities that are therapeutic into the individual's life it would concurrently help prevent further disability and maintain current level of functioning as well as sustain the individual's interest and enthusiasm during a therapeutic activity. (Benda et. al, 2003, 818) Although participation in recreational activities can be beneficial therapeutically, it is also important in terms of your child having a well-rounded life.

There are many things that influence your child's involvement in recreational activities. Some things to consider when choosing a specific activity are your child's mental, sensory, respiratory, cardiovascular, skin structure, and neuromusculoskeletal functions. Mental functions include how they feel, how they think and how they interpret the world around them. Sensory functions are considered when looking at sight, hearing, pain, touch, and how they respond to movement from each recreational activity.

Respiration and heart rate should also be monitored when the recreational activity demands a large amount of energy. Skin structure provides a protective layer for underlying organs. Participation in recreational activities may also require neuromusculoskeletal, or movement related functions. These include the functions of joints, bones, muscles and the corresponding movements (AOTA, 2002).

These factors will influence the type of involvement and the possible adaptations that have to be made for participation in the recreational activity of your child's choice. There are many recreational activities for people with disabilities; the following section describes a variety of recreational activities that are available to your child or adolescent with cerebral palsy.

CHAPTER 3

RECREATIONAL ACTIVITIES

ADAPTIVE ALPINE SKIING

History

Disabled European veterans were the first to discover the benefits of adaptive skiing. After World War II, individuals with disabilities were looking for rehabilitation and recreational opportunities. In 1942, Franz Wendel was the first individual with a disability to enter a skiing competition. Wendel designed a pair of crutches with skis attached to the bottom, allowing him to "crutch ski". By the late 1940's adaptive skiing programs began to develop around the world at army hospitals. (Adaptive Adventures, 2006)

What your child needs to be able to do

Alpine skiing can be adapted to fit the needs of many individuals. In order to get the full experience your child should have good vision, good head control, and fair trunk stability. The level of your child's ability will influence what type of equipment is appropriate for him/her.

Benefits of the activity

- The neuromuscular recruitment needed to perform the activity will increase upper extremity strength and coordination.
- Depending on the level of support needed, lateral movements and muscle contractions for balance will improve trunk stability.
- Skiing will also strengthen an individual's neck and back muscles, promote eye-hand coordination, and provide the individual with proprioceptive and vestibular input.
- Increase confidence and self-esteem

Equipment

Depending on the level of support needed, there are different types of skis. (Less support required → More support required.)

Less support:

Outriggers: A modified version of forearm crutches with ski tips mounted on the bottom. Outriggers provide the skier with increased balance during mobility, and turning. Outriggers are typically used by individuals who normally require the assistance of crutches, or a cane to walk.



Mono-skier with hand-held
outriggers

ADAPTIVE ALPINE SKIING-CONTINUED

Mono-ski: Individuals who use the mono-ski sit in a molded seat that is mounted to a single ski and use hand-held outriggers. The mono-ski requires the greatest strength and balance of any sit-down skiing equipment to operate. The mono-ski is for individuals with lower extremity

More support:

Bi-ski: Individuals who use the bi-ski sit in a rigid seat mounted to two, shorter, wider skis. The bi-ski is used in conjunct with the use of two outriggers. Some individuals use hand-held outriggers, other utilize fixed outriggers that are attached to the base of the bi-ski. For those requiring more assistance, fixed outriggers and a handlebar are normally employed. Whenever fixed outriggers are used, the bi-ski must be tethered by an instructor. The bi-ski provides greater stability than the mono-ski and is typically used by people who use wheelchairs or walk with difficulty using assistive devices.



Bi-skier with fixed outriggers

Resources

- Adaptive Adventures

For more detailed information see Caregiver Resources in Chapter 4

Pictures from <http://www.adaptiveadventures.org/sportsrec/alpine.html>

SLED HOCKEY

History

Sled hockey is usually played by individuals that have lower extremity disabilities. Ice sled (sledge) hockey was invented at a Stockholm, Sweden rehabilitation center in the early 1960s by a group of Swedes who, despite their physical impairment. Sled hockey utilizes a modified metal frame which is attached to two regular sized hockey skates. Sled hockey is very similar to “regular” hockey and has all the basic rules of hockey, with the main difference being the way you maneuver on the ice. (United States Sled Hockey Association, 2006)

What your child needs to be able to do

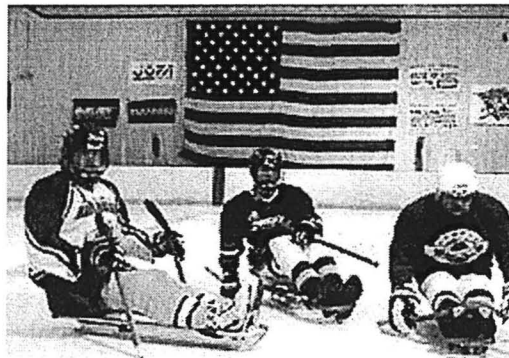
Individuals that participate in this activity should have good muscle strength, range of motion and dexterity in upper extremities. They should also have good trunk stability and balance, as competition sled hockey has regulations on the height of the back support.

Benefits of the activity

- The neuromuscular recruitment needed to perform the activity will increase upper extremity strength and coordination
- Depending on the level of support needed, lateral movements and muscle contractions for balance will improve trunk stability
- Sled hockey will also strengthen an individual’s neck and back muscles, promote eye-hand coordination, and provide the individual with proprioceptive and vestibular input
- Increase confidence and self-esteem

Equipment

- Adapted hockey sticks
- Sleds
- Puck
- Hockey pads
- Ice rink



SLED HOCKEY-CONTINUED

What you do

Players propel themselves by digging the metal picks, which are located on the ends of two short hockey sticks, into the ice and pulling themselves forward. Each player

has a right and a left stick that are copies of miniature hockey sticks. These sticks are used for shooting, passing and propelling the player. Players are seated on the “sleds” which are attached to two hockey skate blades. The sleds are about three inches off the ice and are anywhere between two to four feet long, depending on the size of the player.

The difference between a typical hockey game and a sled hockey game are: instead of twenty minute periods, they are fifteen minutes, two sticks instead of one, the use of the sled. Puck and pads are the same.

Modifications

The typical “sled” does not have a back support, but one can be added for trunk stability. If the player needs more assistance for balance and stability, the blades can be set wide apart. As skills progress, the blades are placed closer together for better turning. There are multiple straps to hold the sled as close as possible to the player, which in turn gives them more control. As with all modifications, make sure to check with supplier and specialist in order to ensure safety and appropriateness.



Resources

- Adaptive Adventures
- United States Sled Hockey Association

For more detailed information see Caregiver Resources in Chapter 4

Pictures from <http://www.adaptiveadventures.org/sportsrec/sledge.html>

HANDCYCLING

History

The United States Handcycling Federation was formed in 1998. It is an alternative cycling sport for individuals who are interested in biking, but have limited lower extremity use. Most handcycles have three wheels instead of two and allow the biker to peddle and steer the bike using only their upper body. Hundreds of individuals enjoy handcycling throughout the world from elite athletes to individuals who enjoy it for recreational purposes. (USHF, 2006)

What your child needs to be able to do

Your child needs to have good upper body strength and coordination. They should also have good trunk stability and balance.

Benefits of the activity

- Handcycling provides the individual utilizing the bike cardiovascular as well as physical conditioning.
- It also increases upper extremity strength and coordination.
- Increase confidence and self-esteem

Equipment

Thanks to modern technology, handcycles come in a variety of styles, making them accessible to people of all abilities. The level of assistance required and what level of cycling done influences the type of bike that is appropriate for the individual. (Recreation vs. Competition)

Upright vs. Recumbent Handcycles

Uprights are easier to transfer to and balance on, and their higher profile makes them more visible in traffic. Recumbent handcycles may put the torso in a reclining position, with legs out in front of the individual.

Lean vs. Pivot Steering

All uprights are pivot-steer, that is the front wheel turns while the rest of the bike remains upright. Lean-to-steer handcycles are turned in part by leaning the cycle.



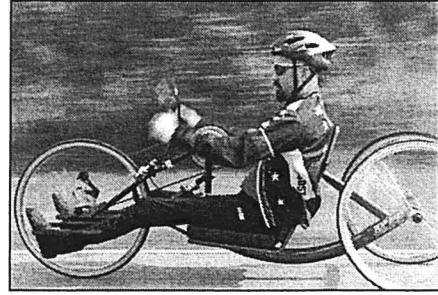
Upright pivot-steer handcycle

HANDCYCLING-CONTINUED

An upright, pivot steering handcycle provides the most support in terms of balance and stability. The recumbent lean-to-steer handcycles are faster, have more gearing and are lighter, but can be problematic for decreased trunk stability.

Modifications

The type of bike chosen will influence the level of assistance the handcycle will provide. Straps may be added to foot/leg rests to secure them safely in place. Lateral supports and head rests may also be added if appropriate for the individual's needs. As skills progress or interest in handcycling competition occurs, the individual may choose different options in terms of bikes and equipment. As with all modifications, make sure to check with supplier and specialist in order to ensure safety and appropriateness.



Lean-to-steer recumbent bike

Resources

- **Adaptive Adventures**
- **United States Handcycling Federation (USHF)**

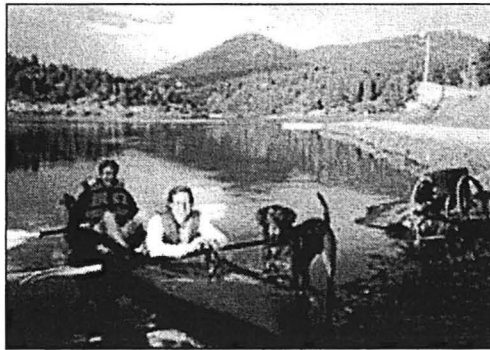
For more detailed information see Caregiver Resources in Chapter 4

Pictures from <http://www.ushf.org/handcycling101.html>

ADAPTIVE CANOEING, KAYAKING AND RAFTING

History

Paddle sports are growing in popularity because it is something that people of all abilities can enjoy. The relative affordability, ease of paddling and simple modifications that can be made so all individuals can participate make it especially attractive. Canoes, kayaks and rafts come in different lengths, widths and hull shapes. Each piece of equipment comes in different types, which allow for tandem, two people, to paddle and maneuver the vessel. This is an advantage for people with visual impairments and for individuals who can only generate limited paddling power.



What your child needs to be able to do

This activity can be adapted to fit the needs of everyone!

Benefits of the activity

- Paddle sports provide cardiovascular exercise, development of skills, experiencing nature, and provide the individual with proprioceptive and vestibular input
- These activities will also strengthen upper extremities as well as increase upper extremity coordination
- Lateral movements and muscle contractions required to balance during paddling will improve trunk stability
- Increase self-esteem and confidence

ADAPTIVE CANOEING, KAYAKING AND RAFTING- CONTINUED

Equipment

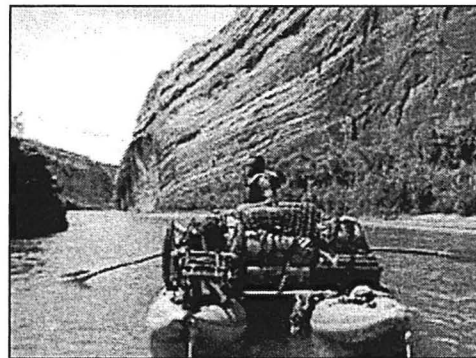
Depending on your child's ability, standard equipment may be used without making adaptations or requiring the use of specialized equipment. Other situations may only require minimal adaptations in order for the individual with cerebral palsy to participate. Various changes to seating systems, paddle grips, and leg position can allow these individuals the opportunity to experience these paddle sports. If necessary, other types of adaptive paddling equipment are available.

Sit-on top kayaks

Also known as open-decked kayaks, sit-on top kayaks work well in warm climates, and for individuals that need little seating adaptation. Biggest ease is that the individual is able to get on and off easily. This type of kayak is not advantageous for anyone who has poor sitting balance or decreased trunk stability because of the higher center of gravity it demands.

Inflatable kayaks- "Duckies"

Duckies are utilized by individuals who have balance deficits. These kayaks are easy to adapt with seating systems, and provide increased stability. One downfall of the inflatable kayaks is that they catch wind easily and become difficult to maneuver.



Inflatable kayaks

Modifications

The type of paddle boat chosen will influence the level of assistance the boat will provide. Adaptations to the seating system can be made by adding lateral supports and straps to increase stability and balance. Standard paddles can be easily adapted by using gripping materials or pieces of bike tubing.

Resources

- **Adaptive Adventures**
- **American Canoe Association (ACA)**

For more detailed information see Caregiver Resources in Chapter 4

Pictures from <http://www.adaptiveadventures.org/sportsrec/paddle.html#history>

ADAPTIVE WATER-SKIING

History

In 1986 Jeffry Armstrong, USA Water Ski President, appointed an National Disabled Committee. The first tournament for disabled skiers was held in 1989 in Dearborn, Michigan. (www.waterskiingsite.com, 2005).

What your child needs to be able to do

Adapted water-skiing can be adapted to fit the needs of many individuals. In order to get the full experience your child should have good vision, good head control, and fair trunk stability. The level of your child's ability will influence what type of equipment is appropriate for him/her.

Benefits of the activity

- The neuromuscular recruitment needed to perform the activity will increase upper extremity strength and coordination
- Depending on the level of support needed, lateral movements and muscle contractions for balance will improve trunk stability
- Adaptive water-skiing will also strengthen an individual's neck and back muscles, promote eye-hand coordination, and provide the individual with proprioceptive and vestibular input
- Increase confidence and self-esteem

Equipment

Sit Skis

Comp 1 Kanski by Quickie Design/Sunrise Medical

The Comp 1 Kanski can be used from beginner to competition level skiing. It comes with many inserts that make adapting it to individual needs easy.

Kiestead Skis

Developed through collaboration with a speed ski manufacturer and world champion sit skier. It is similar to the Comp 1 Kanski in width, but is three inches longer, and seven pounds lighter.



ADAPTIVE WATER-SKIING – CONTINUED

Kiestead Skis-continued

This option is for the more advanced individual as it requires more balance and coordination. There are bevels on the ski that give it superior edge changes and wake crossings.

Modifications

The model of ski chosen will influence the type and amount of adaptations that are possible. The Comp 1 Kanski comes with inserts that can be used to give the appropriate amount of assistance for each individual. These inserts also allow for adjustability in mounting the seat as well as the footplates.

Resources

- **Adaptive Adventures**

For more detailed information see Caregiver Resources in Chapter 4

Picture from <http://www.adaptiveadventures.org/sportsrec/waterski.html>

SCUBA DIVING

History

The Handicapped Scuba Association (HSA) was founded in 1981 and is now the leader for recreational diving for people with disabilities (HSA, 2006). Scuba diving is relaxing and be enjoyed by individuals with all levels of abilities.

What your child needs to be able to do

First off, you child needs to be comfortable in the water and have good respiratory functions. Your child must also be able to keep the mouthpiece in their mouth. Many adaptations can be made to make this easier. This activity can be modified to meet the needs of most populations.

Benefits of the activity

- Scuba diving provides cardiovascular exercise
- Development of new skills
- Provides the individual with proprioceptive and vestibular input
- It also may give the individual a feeling of freedom because it affords them the opportunity to move about without a wheelchair or an assisted device they rely on while on land.
- Increase confidence and self-esteem



Equipment

- Wetsuits- Forms a layer of protection for the body against abrasions. Also helps create barrier to heat exchange in cold water.
- Tanks- Comes in a variety of forms. Aluminum is lighter than its steel counterpart. When an aluminum tank is empty it floats, while steel will sink.

SCUBA DIVING – CONTINUED

Equipment-continued

- **Regulator**-The regulator is the breathing apparatus. It is very lightweight and provides very high breathing capacity. The mouthpiece has a comfort bit (which can be formed to the individuals mouth) to help people with oral-motor problems keep the regulator in place.
- **Buoyancy Control Device (BCD)** - BCD's along with weight belts provide control and balance during all parts of the dive.

Other information

HSA implements a physical performance standard that categorizes the diver according to their abilities. For instance; a Level A diver is certified to dive with one other person, a Level B diver must dive with two other able-bodied divers and a Level C diver also requires two dive buddies, but one must be trained in diver rescue.

There are safety concerns for every individual in Scuba, but there are some personal safety issues specifically for individuals with disabilities. These areas include; use of medication, skin protection, pulmonary conditions, and temperature regulation. Individuals should get full medical clearance from their personal physician before diving.

Modifications

Because the water greatly reduces mobility problems, it can be taught to individuals with disabilities with virtually no modifications. Modifications and assistance may be needed to access the dive platform and to exit the water. If the individual does require assistance with propulsion, there is a hand held propeller that one can utilize.

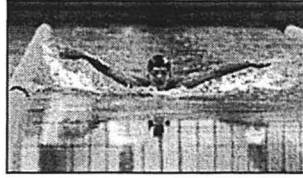
Resources

- **Adaptive Adventures**
- **Handicapped Scuba Association (HSA)**

For more detailed information see Caregiver Resources in Chapter 4

Picture from <http://www.adaptiveadventures.org/links/scubalinks.html>

SWIMMING



History

Swimming is a great recreational can be done indoors or outdoors. Swimming can be done in a variety of contexts. It may be done solely for therapeutic reasons (aqua therapy), for competition, or purely for recreation.

What your child needs to be able to do

Everybody can be included! This activity can be adapted to fit the needs of almost every individual. There are benefits to all populations and levels of cerebral palsy involvement.

Benefits of the activity

- Gives the individual the opportunity to become comfortable in water, which may create interests in other water sports such as kayaking or skiing
- Provides cardiovascular exercise
- Water reduces stress on joints
- Low impact (weight in water is 10% of normal weight) (United Cerebral Palsy, 2006)
- Water produces resistance which will increase muscle strength
- Improves balance and agility
- Provides the individual with proprioceptive and vestibular input
- Increase confidence and self-esteem

Equipment

There is not a lot of equipment needs for the basics of this activity. Equipment may only consist of a swimsuit. Depending on needs of each individual, further equipment may be utilized to access or participate in swimming.

SWIMMING – CONTINUED

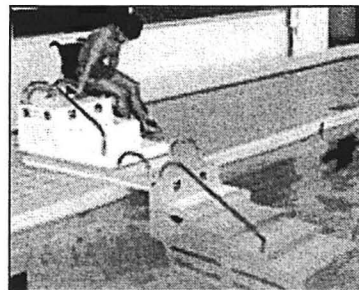
Modifications

Access-Because access to the environment or the activities for individuals with cerebral palsy may be difficult, there are a number of different modifications that can be made in this area. A ramp or a stair system can be utilized to assist the individual with accessing the pool. For access to a lake or a natural body of water, an all-terrain wheelchair may be used.



All-terrain
wheelchair

Stair system



Assistance-If the individual with cerebral palsy is highly involved, it is recommended that another person be with them at all times while they are near or in the water. This person should be comfortable in and around the water, and be CPR certified.

Equipment-Floatation devices may be used in conjunct with supervision from another individual. These floatation devices help stabilize all individuals, no matter what their impairment.

Resources

- Adaptive Adventures
- United Cerebral Palsy (UCP)

For more detailed information see Caregiver Resources in Chapter 4

Pictures take from http://www.ucp.org/ucp_channel.doc.cfm/1/15/11383/11383-11383/2846

WHEELCHAIR BASKETBALL

History

According to the National Wheelchair Basketball Association (NWBA), wheelchair basketball started in the Veteran Administration Hospitals in 1946. The National Wheelchair Basketball Association was founded in 1948, and is the nation's oldest and largest disability sport organization. (NWBA, 2006).

What your child needs to be able to do

Individuals that participate in this activity should have lower extremity limitations, but have good upper body strength and coordination. They should also have fair trunk stability.

Benefits of the activity

- Provides the individual with proprioceptive and vestibular input
- Provides cardiovascular exercise
- Increase upper extremity muscle strength
- Increase hand-eye coordination
- Promote social interaction
- Increase confidence and self-esteem



WHEELCHAIR BASKETBALL – CONTINUED

Equipment

In order to participate in wheelchair basketball, the individual needs his/her own wheelchair, a basketball, and a basketball hoop.

What you do

Players are classified into three categories according to their abilities. Most of the rules are comparable to the rules of standard basketball, but there are many adaptations to the physical game of basketball in the wheelchair version. In order to play regulation wheelchair basket ball, refer to the most recent Official Rules and Case Book or to the NWBA national website for detailed information.

Modifications

Most modifications to this activity are done to the wheelchair system. Straps may be added to the footplates to secure feet/legs. Lateral supports, and harnesses may be added in order to increase trunk stability. When making modifications it is important to refer to the Official Rules and Case Book so as not to violate any rules or regulations.

Resources

- **National Wheelchair Basketball Association (NWBA)**

For more detailed information see Caregiver Resources in Chapter 4

Pictures from

<http://www.nwba.org/index.php?module=ContentExpress&func=display&ceid=13>

HORSEBACK RIDING

History

According to the North American Riding for the Handicapped Association ([NARHA], 2006), horseback riding for therapeutic reasons was first introduced into the United States in the late 1960's. Horseback riding can be done in many different contexts. Hippotherapy is therapy that includes horses as a mediums utilized during intervention. There is a therapist, and usually two side-walkers that provide assistance and therapy while the individual is positioned on the horse. There are also therapeutic riding programs where an individual, who is educated on the benefits of horseback riding, teaches the proper riding techniques to the rider. This usually does not include a therapist.

What your child needs to be able to do

Depending on the type of horseback riding chosen (hippotherapy, therapeutic riding or recreational riding), the individuals that participate in this activity should have good upper body strength and coordination. They should also have fair trunk stability. If the child needs more assistance, hippotherapy (hands on therapy that offers the most assistance) would be the best option.

Benefits of the activity

- Provides the individual with proprioceptive and vestibular input
- Improve balance
- Increase muscle strength
- Increase hand-eye coordination
- Promote emotional connections with the animal
- Increase confidence

Equipment

Depending on the type of horseback riding decided, equipment needs change. Equipment will usually be provided by the hippotherapy or therapeutic riding organizations, but may be an additional cost.

Recreational riding

- Horse
- Saddle
- Saddle blanket
- Bit
- Reins
- Appropriate clothing



HORSEBACK RIDING - CONTINUED

What you do

The rider sits in the middle of the horses back with good posture. Focus is on symmetrical movements, and increase in coordination and posture.

Modifications

Modifications may include the level of assistance required for the rider to be safe during the activity. This can be from them riding independently, to a horse leader and two side-walkers. In order to increase stability, you may also want to try a saddle with suede or synthetic cover so the rider will “stick” to the saddle better.

Resources

- North American Riding for the Handicapped Association, Inc.

For more detailed information see Caregiver Resources in Chapter 4

Picture from http://www.nscd.org/pictures/riding_4.jpg

CHAPTER 4

CAREGIVER RESOURCES

PEOPLE WHO ARE INTERESTED IN GETTING YOUR CHILD INVOLVED IN RECREATIONAL ACTIVITIES!

Organizations

Adaptive Adventures

National Office (Evergreen, Colorado):

P.O. Box 2245

Evergreen, CO 80437

Phone: 303.679.2770

Director's Phone: 866.679.2770

Toll Free: 877.679.2770

Fax: 303.670.8290

Email queries: info@adaptiveadventures.org

Physical Address:

27888 Meadow Drive

Evergreen, CO 80439

Website: <http://www.adaptiveadventures.org>

Adaptive Adventures is a non-profit organization dedicated to improving the lives of children and adults with disabilities and their families through outdoor sports & recreation. The organization was created in 1999 by a group of physically challenged individuals who saw the need to increase awareness and participation in sports and recreation for the disabled. Adaptive Adventures is considered a national leader in the areas of adaptive cycling, water-skiing, paddling and winter sports.

American Canoe Association (ACA)

Website: <http://www.acanet.org>

The ACA offers advice, instruction, referrals and information for individuals interested in paddle sports. For experienced paddlers, ACA will offer resources, suggestions and information on skills courses, and Instructor Certification.

Handicapped Scuba Association (HSA)

HSA International

1104 El Prado

San Clemente, CA 92672-4637

Telephone: (949) 498-4540

Fax: (949) 498-6128

Website: <http://www.hsascuba.com>

"Founded in 1981, The Handicapped Scuba Association, a non-profit organization, has dedicated itself to improving the physical and social well being of people with disabilities through the exhilarating sport of scuba diving and in doing so has become the worldwide authority in the field."

National Wheelchair Basketball Association (NWBA)

6165 Lehman Drive Suite 101
Colorado Springs, CO 80918
Telephone: (719) 266-4082
Website: <http://www.nwba.org>

North American Riding for the Handicapped Association (NARHA), Inc.

PO Box 33150
Denver, Colorado 80233
Telephone: 800-369-RIDE (7433)
Fax: (303) 252-4610
Website: NARHA@NARHA.ORG

United Cerebral Palsy (UCP)

Website: <http://www.ucp.org>
© 2005, UCP National Site
1660 L Street, NW, Suite 700, Washington, DC 20036
Phone: (800) 872-5827/(202) 776-0406 TTY: (202) 973-7197 Fax: (202) 776-0414
E-Mail: webmaster@ucp.org

United States Handcycling Federation (USHF)

P.O. Box 3538
Evergreen, CO 80437
Telephone: (303) 679.2770
E-mail: info@ushf.org
Website: www.ushf.org

The USHF is the official governing body for the development of hand cycling in America in both recreational and competitive natures. USHF conducts several clinics and competitions throughout the year.

United States Sled Hockey Association (USSHA)

President: Joe Lambert
2236 E. 46th St.
Davenport, IA 52807
(H) 563-344-9064
(W) 309-762-7716
Website: www.usahockey.com/ussaha/main_site/main/home

EQUIPMENT THAT WILL HELP YOUR CHILD BECOME INVOLVED IN RECREATIONAL ACTIVITIES!

Equipment

Adaptive Bikes

Action Top End

4501 63rd Circle North
Pinellas Park, FL 34665
Telephone: (800) 532-8677

Bike-on.com

54 Tiffany Road
Coventry, RI 02816
Telephone: (888) 424-5366

Creative Mobility

2930 Campton Hills Road
St. Charles, IL 60175
Fax: (630) 584-1295
Telephone: (800) 711-2453

Sports Wheelchair

Sunrise Medical

Sunrise Medical
7477 East Dry Creek Parkway
Longmont, CO 80503
Telephone: (888) 333-2572

TiSport

1426 East 3rd Ave.
Kennewick, WA 99337
Telephone: (800) 545-2266

Water-ski

Quickie Water-skis

Sunrise Medical
7477 East Dry Creek Parkway
Longmont, CO 80503
Telephone: (888) 333-2572

Kierstead Skis

Telephone: (321) 259-6737

Alpine Skiing***Mono-ski*****Freedom Factory**

1943 Karen Circle

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Unique Inventions

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CHAPTER V

SUMMARY

Having a diagnosis of cerebral palsy has an effect on many areas in an individual's life. The focus of this project was on the ability of an individual with a diagnosis of cerebral palsy to access and participate in recreational leisure opportunities. Participation or the lack thereof, in these activities influences the individual's social interaction, and his or her perceived level of independence and self-esteem. Many barriers that cause access and participation in recreational opportunities to become difficult exist for individuals with cerebral palsy; the most obvious barrier is the physical limitations that may exist. The individual with cerebral palsy may also have difficulty trying novel activities secondary to low self-esteem. According to the literature review, the general public's perceptions of cerebral palsy include a lot of misconceptions. These negative connotations may lead to a stigmatization of persons with cerebral palsy, thus creating a barrier to participation.

Without proper intervention, this decreased participation in recreational and leisure opportunities may lead to a decrease in the individual's quality of life. Through a review of literature, it has been identified that there is a need for a caregiver-friendly resource that can educate the reader on the benefits of recreation and help the caregiver locate organizations and equipment that are specific to the population with cerebral palsy. Therefore, a recreational manual for caregivers of individuals with cerebral palsy was developed as a resource for occupational therapists to give to parents and caregivers to

help them gain knowledge and resources regarding access and participation opportunities in recreational and leisure activities for their child or adolescent.

Limitations of this project include a lack of evidence-based research in the area of recreation and leisure and individuals with cerebral palsy. Due to this lack of research, there is also a lack of current literature and information written about recreational activities and their benefits for this population. Another limitation is an absence of outcome measures to identify participation/access and satisfaction levels to recreational opportunities for this group. These limitations result in inadequate descriptive research information, which is needed to identify the magnitude of the problem. The data that can be gathered through further research will aid in the design and implementation of a comprehensive intervention that is client-centered and focused on recreational opportunities and their benefits. An additional limitation is that the manual has not been used in a practice setting and therefore, research on the effectiveness of the use of the manual has not been implemented.

In order to implement this project, the author needs to collaborate with other occupational therapists. Because this manual is caregiver friendly, therapists can distribute it in a number of different locations and to other healthcare professionals. Healthcare professionals are able to identify the appropriate population, and give the manual to parents and caregivers as a resource. The manual can also be used by occupational therapists to give to local community recreation organizations to educate them on recreational opportunities for individuals with physical impairments, as well as to be a resource for them to give to individuals inquiring about recreational opportunities.

Occupational therapists address a variety of aspects of daily living to enhance independence and quality of life. A vital aspect of occupational therapy is providing a holistic and client-centered approach to treatment. An important, but often neglected, area of occupational intervention is the aspect regarding recreational opportunities. With the implementation of the use of this recreational manual for caregivers of individuals with cerebral palsy, many things can be accomplished. Readers will be educated on the benefits of recreational opportunities, they will have information on how to find resources for access and participation in appropriate activities, and individuals who do take advantage of the opportunities should experience an increased level of independence as well as enhanced self-esteem. It is important for the development of children and adolescents with cerebral palsy that they have social support and access to activities they enjoy in addition to medical services. "By incorporating recreational activities that are therapeutic into the individual's life it would concurrently help prevent further disability and maintain current level of functioning as well as sustain the individual's interest and enthusiasm during a therapeutic activity" (Benda et al., 2003, p. 818).

Recommendations for the future include: 1) additional research regarding recreation and its benefits for individuals with disabilities, 2) research to identify the outcomes when recreational opportunities are provided for individuals with disabilities, 3) current resources about recreation and leisure opportunities should be provided to individuals with disabilities and their caregivers, and 4) research to determine the effectiveness of use of the recreation manual.

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